Consultation on Disability Royal Commission Response

January 2024

Contents

About VALID

VALID is the peak organisation in the Victorian disability sector representing adults with intellectual disability and their families. VALID has been run by and for people with disability and their family members for over 30 years. During this time, VALID has developed expertise in networking, information provision and project management to people with disability and families across Victoria. VALID has four main program areas:

1. **Self Advocacy**

VALID's Self Advocacy team supports people with intellectual disability in a range of ways to become strong self advocates. One way the Self Advocacy team does this is by working alongside VALID staff with intellectual disability in the VALID8 team to review group homes and report on self-advocacy practice to service providers and the Department of Families, Fairness and Housing (DFFH).

2. **Community Development**

VALID's Community Development team works to build more inclusive communities so people with disability can live lives of their choosing. They take a multi-level approach to creating change in the broader community that works at individual, group and community levels.

3. **Training and Consultations**

VALID's Training and Consultations team runs courses for people with disability, family members and support staff. This team focuses on empowerment, accessibility and safety of people with disability. They also run focus groups that give people with disability and their families a chance to have their voices heard on different topics.

4. **Individual Advocacy**

VALID's Individual Advocacy team is funded by the Victorian State Government to work with individuals to help solve a specific problem they are experiencing. Cases that involve abuse, neglect and human rights violations are prioritised.

Individual Advocacy helps people speak up about what they want, get the information they need to make their own decisions, and explore the choices they want to make. VALID also supports family members of people with intellectual disability as they advocate for or with someone.

Executive Summary

The DRC Recommendations have the potential to drive strong, positive change. But without enough preparation and funding, these recommendations will not work in practice.

In this response, VALID has discussed and provided Case Studies and its own recommendations in response to the Disability Royal Commission (DRC)'s recommendations on education, employment and all the recommendations as a whole.

VALID has not provided a position on whether special/segregated settings should be phased out. VALID believes that DRC Recommendations along these lines are not necessarily unreasonable and acknowledges that support within many of these settings – and the very nature of segregation – have caused great harm to people with disability. This is unacceptable.

Therefore, we believe that if the Government implements the recommendations to phase out special/segregated settings, it should do so with close attention to the complexities that drive their ongoing existence and proliferation. This is to minimise the potential for further trauma to people with disability who currently study, work and live within these settings.

Overall comment on DRC recommendations and Child Protection Services (CPS)

VALID notes that not many of the recommendations address issues that parents with intellectual disability face with CPS. We receive multiple advocacy requests from parents with serious issues involving both the justice system and CPS. These issues not only breach the human rights of parents with intellectual disability, but also of their children who have the right to be raised by their parents when this is a safe option with or without additional support. We believe this issue needed more focus in the recommendations.

VALID Recommendation 1

Federal and State Governments should work together to ensure a cohesive and fair approach to supporting parents with intellectual disability to raise their children in safe and loving homes.

This response will now discuss the issues and challenges – and provide its own recommendations – in response to the DRC's recommendations around violence, abuse, neglect and exploitation of people with disability.

Education

DRC Recommendation 7.14: Phasing out and ending special/segregated education

VALID's position is that if the Government accepts this recommendation, it needs to direct its implementation with the understanding that the full inclusion of people with disability in society starts with education. Therefore, this recommendation would need to be implemented proactively and to prioritise the specific needs of each student – needs that are identified by the student, their primary carer and educators; not assumed by their educators or the Department of Education. This DRC Recommendation should not be implemented superficially, in a tokenistic way, or with an eye to excessive cost-cutting.

For this recommendation to drive positive change that does not result in further trauma for people with disability, it would need to be implemented with an understanding of the complexities of social exclusion in many people's histories, and likely futures. An example of such complexity is that a person's behaviour might express distress ('behaviours of concern') in community settings where such behaviour is often understood as inappropriate or potentially criminal rather than as a response to experiences of violence, abuse, neglect and exploitation. Such experiences can be overt or covert. They start with the extremely low expectations some professionals place on the potential of newborn and very young children with disability, and culminate in the deskilling of many people with disability in disability-specific services such as Day Services, which many students move on to after leaving special/segregated education settings. Many of these services provide centre-based 'activities' that focus on what the service can do rather than individually tailoring support with a genuine focus on each individual's needs.

DRC Recommendation 7.14 would also need to be implemented with the understanding that such complexities can have negative implications on how people with disability experience 'full inclusion', largely based on how the mainstream or general community responds to them. The below case study gives an overview of such issues in the context of housing. However, the issues raised are the result of a lifetime of segregated settings that begin with the education system.

Case Study

A person with intellectual disability moved into their own home after a long period of living in a group home. The disability support funding they were given was mainly around staff support, with none provided to strengthen their informal networks. This resulted in negative responses and abuse from the community when the person moved in. They became socially isolated, their mental health deteriorated, their dependence on staff increased and they contemplated returning to a segregated housing option.

This demonstrates the potential lifelong implications of segregation: VALID has seen that once people have studied, worked and lived in segregated environments for a long time, the community does not automatically provide informal support when people move into mainstream settings. So in addition to asking what disability-specific support people with disability need in order to have an overall positive experience in mainstream settings, it also needs to be considered what the

mainstream or general community needs to do to facilitate the genuine inclusion of people with additional support needs.

DRC Recommendation 7.5: Careers guidance and transition support services provides some good guidance around how to support high school students with disability in mainstream settings. However, systems including education and many Disability Employment Services (DES) have substantial issues that need to be addressed. We discuss DES further in the Employment section of this response.

VALID Recommendation 2

If **DRC Recommendation 7.14** is accepted by the Government, safeguards, sector and community responses to issues and challenges need to be developed. These responses should minimise or eliminate the negative impacts on students with disability and the community. Implementation of **DRC Recommendation 7.13: National Roadmap to Inclusive Education** should address this.

Employment

DRC Recommendation 7.24: Convene a Disability Employment Rights Council

The Commissioners correctly identified that the main barriers to employment for people with disability are people's attitudes about disability, physical barriers and how businesses and the government work. VALID proposes that additional barriers that exist for people with psychosocial disability should be added to this list: mental barriers and people's psychological capacity to engage in the work at hand.

VALID Recommendation 3

If the Government accepts **DRC Recommendation 7.24**, mental barriers and people's psychological capacity to engage in a given role should be considered alongside those already identified by the Commissioners.

> - **DRC Recommendation 7.17: Develop education and training resources for Disability Employment Services staff**
> - **DRC Recommendation 7.28: Improve information about wages and the Disability Support Pension**
> - **DRC Recommendation 7.29: Embed an 'open employment first' approach in the NDIS Participant Employment Strategy**
> - **DRC Recommendation 7.30: Support the transition to inclusive employment**
> - **DRC Recommendation 7.32: End segregated employment by 2034**

The above recommendations focus on supporting people with disability to understand the infrastructure that supports open employment. VALID believes these recommendations are appropriate. This is because the current infrastructure is highly fragmented, complicated and intimidating for people with intellectual disability and their support networks to navigate.

Case Study

A person with intellectual disability associated with VALID works in an Australian Disability Enterprise (ADE) multiple days per week, and in open employment one day per week. What this person earns in their open employment role is more than they receive for the multiple days worked at an ADE. They want to work more hours but are concerned they may lose their Disability Support Pension (DSP).

Regarding **DRC Recommendation 7.32**, VALID's position is that if the Government accepts this recommendation, it needs to be implemented with deep understanding of and a practical response to the substantial barriers to sustainable open employment for people with intellectual disability. Based on the above recommendations, this response needs to address educating and supporting people to navigate the current infrastructure with less worry and fear – for example, regarding Centrelink reporting requirements. It also needs to have a strong focus on sustained and co-designed efforts to improve infrastructure and introduce more flexibility into rigid systems that do not work for people with intellectual disability. For example, if a person with intellectual disability does not have their Birth Certificate, Driver's License or other photographic identification, it can be near-impossible for them to fulfil all the requirements to undertake open employment.

VALID Recommendation 4

Supporting people with disability to understand the current infrastructure that supports open employment is a good start. VALID's recommendation is that sustained and co-designed efforts are undertaken to improve this infrastructure. This infrastructure includes, but is not limited to, Centrelink and Disability Employment Services (DES).

Regarding **DRC Recommendation 7.17**, VALID has identified a recurring pattern over many years that some DES will only support people with lower support needs to gain and maintain open employment. Because there is a financial incentive for DES to successfully 'place' people in roles, there is a tendency for some not to accept the responsibility of supporting people with higher support needs into open employment because of how long this can take.

VALID Recommendation 5

DRC Recommendation 7.17 needs to include a practical focus on ensuring that DES are equipped, willing and ready to competently support people with higher support needs into open employment.

DRC Recommendations 7.18 – 7.22

These Recommendations focus on ensuring the Australian and State Public Services increase the number of people with disability they employ. VALID would like to add to these by sharing information about its own VALID8 team that employs people with intellectual disability. This information illustrates some of the positive and negative impacts on employees with disability that can result from forward-thinking, yet inflexible, government policy.

> **Case Study**
>
> The VALID8 team is made up of staff with intellectual disability who review group homes and report on self-advocacy practice to service providers and DFFH. The roles have been funded by DFFH on a short-term basis over a number of years. The purpose of this is to enable as many people with intellectual disability as possible to experience the benefits of open employment, which is being achieved. In this sense, the VALID8 team has been successful despite the substantial challenges presented by COVID-19.
>
> There are also negative elements in the VALID8 team's experience. The impact of a short-term role of this nature on the lives of people who have generally only lived and worked in segregated settings is that their skills and confidence start to develop strongly towards the end of their contracts. This means they develop enough skills and confidence to understand that they are valuable members of the team, but not enough to sustain this momentum on their own, or even with the support of the existing disability employment support infrastructure.

This case study is relevant because even when people with intellectual disability successfully navigate the barriers to gaining and maintaining open employment, its structure can cause harm if it is not carefully designed in consultation with people with intellectual disability, their supporters, employers and government.

VALID Recommendation 6

Funding structures to increase open employment opportunities for people with intellectual disability should be carefully designed in consultation with people with intellectual disability, their supporters, employers and government.

> **DRC Recommendation 7.31: Raise subminimum wages**
>
> **DRC Recommendation 7.32: End segregated employment by 2034**

Australian Disability Enterprises (ADEs)

VALID believes that subminimum wages should be raised. At the same time, VALID has concerns that an increase in the subminimum wage for people with disability, combined with the fragmented, complicated and intimidating nature of open employment for people with disability, might result in fewer people with intellectual disability having any form of employment at all. Therefore, the raising of subminimum wages needs to be done with full awareness of the potential unintended consequences for employees with intellectual disability, particularly people with higher support needs. The government needs to work early and in collaboration with people with disability and their support networks to counter these potential consequences.

Case Study

VALID staff know of people with disability who work in ADEs counting chocolate bars. When asked whether people enjoyed this work, staff reported that people responded with comments such as 'it's somewhere to go', 'my friends go there', and 'if I could get out in the real world, I would.'

These consequences exist in part because the ADE business model does not incentivise ADEs to increase the subminimum wage or support good workers into open employment. This is because ADEs provide products for competitive prices, and these products are in public demand. This demand is driven in part by the products' pricing, in part because ADEs are perceived to be doing a good thing by employing people with intellectual disability, and in part because people with intellectual disability are enabled to work. However, this work pays subminimum wages, and employees possibly use their NDIS funds to support them to work there.

Volunteer and work experience roles for people with intellectual disability within mainstream workforces

A similar issue exists in mainstream workforces providing volunteer and work experience roles for people with intellectual disability. VALID is aware of examples of 'employee' retention that show the ongoing exploitation of people's skills with reduced or no financial compensation.

At present these are the only practical opportunities for some people with intellectual disability to gain any form of experience and/or financial compensation (e.g. a work experience daily payrate). This is in part because when other organisations such as local councils are incentivised to hire people with disability and people from other marginalised groups, it is rare that they will hire people with intellectual disability. These organisations will at times claim that hiring someone with intellectual disability means that people from other marginalised groups miss out.

VALID believes that people with intellectual disability deserve better pay and more opportunities than ADEs, and exploitative volunteer and work experience roles within mainstream workforces, can offer. Without appropriate and ongoing awareness and practical action, the risk is that without these options, people will lose their roles, skills and more.

Case Study

VALID is aware of cases in which people with disability work alongside colleagues without intellectual disability doing the same hard, physical labor, and are paid less than their colleagues.

VALID Recommendation 7

If the Government accepts **DRC Recommendation 7.31**, it needs to direct its implementation with deep understanding of and practical responses to the potential unintended consequences.

VALID Recommendation 8

If the Government accepts **DRC Recommendation 7.32**, it needs to direct its implementation with deep understanding of and practical responses to the needs of people with intellectual disability with higher support needs.

All DRC Recommendations

Volume 4: Realising the human rights of people with disability

Volume 5: Governing for inclusion

Volume 6: Enabling autonomy and access

Volume 7: Inclusive education, employment and housing

Volume 8: Criminal justice and people with disability

Volume 9: First Nations people with disability

Volume 10: Disability services

Volume 11: Independent oversight and complaint mechanisms

Volume 12: Beyond the Royal Commission

The DRC has made many sound recommendations for change with the aim of eliminating violence, abuse, neglect and exploitation against people with disability. This is cause for some optimism.

However, there is also cause for significant concern. This is due to at least three factors: concerns regarding the NDIS Quality and Safeguards Commission (NDIS Q&SC), a lack of trauma-informed support and training for people with disability and their supporters, and insufficient funding for independent advocacy services.

The NDIS Q&SC is not equipped to support people with disability, their families or support networks when in crisis.

Trauma-informed support for people with disability and their support networks is critical because many people have experienced violence, abuse, neglect and exploitation throughout their lives. Without competent trauma-informed support, some people with disability and their family members may express high levels of distress when exposed to disability systems that further compound their trauma. This is entirely reasonable. In many cases the only ways that people with disability can communicate their distress are termed 'behaviours of concern' which are then 'treated' by professionals via restrictive practice (discussed in **Volume 6**: **Enabling autonomy and access**).

VALID supports DRC Recommendations that discuss legal changes to restraint of people with disability. However, we can only support these alongside recommending substantial changes to the NDIS Q&SC, which currently lacks adequate capacity to work alongside and manage support for people with disability and their supporters, who have often experienced deep trauma. VALID notes the NDIS Q&SC has not demonstrated the capacity or willingness to educate and support Support Coordinators, Support Workers and other frontline professionals on how to work with people with disability and families responding to trauma in ways that come across as 'difficult' or 'troublemaking'. This support needs to focus on how people with disabilities and families have been impacted by trauma rather than the impact of such behaviours on professionals. Without widespread education and support of this nature, legal changes in how restraint is to be administered, reduced or eliminated could mean that professionals seek other, legal ways to restrain people (e.g. chemical

restraint through seeking mental health diagnoses) or that the risk of harm to people with disability and their supporters increases in the absence of appropriate support.

Case Study

VALID has been advocating for and with a person with disability and their family around their experiences with each other, a service provider and the NDIS Q&SC. Because the NDIS Q&SC staff member has not taken a trauma-informed approach to their role in this family's lives, their responses to serious issues have inflamed an already serious situation.

Despite an investigation, the NDIS Q&SC has not taken appropriate action to support the person with disability or their family. This case study is not unique.

This demonstrates a lack of capacity of the NDIS Q&SC to provide effective trauma-informed support. In turn, this means that when people with more complex issues talk to the NDIS Q&SC about their issues, the NDIS Q&SC does not take action, or the communication and actions taken by the NDIS Q&SC create more problems.

VALID Recommendation 9

Legal changes to restraint of people with disability (**Volume 6**) must be considered alongside changes to the NDIS Q&SC that focus on their capacity to support people with disability, their families and support networks when in crisis. This should include a significant focus on the provision of high-quality trauma-informed support.

People with disability, their families and support networks are not receiving trauma-informed support and training.

VALID sees a need for improved trauma-informed practice not only from the NDIS Q&SC, but also from service providers and Support Coordinators. Unfortunately, this issue is further compounded by support providers not speaking up to their managers about challenging interactions between themselves and people with disability and family members because they feel afraid that they will be blamed. This issue is widespread and means that systemic issues preventing support providers from better supporting people are not addressed. This means that at a systemic level, a punitive response to this issue will not be effective.

Unaddressed complexities at both the systemic and individual levels around working with people with higher support needs and complex trauma include a lack of funding for independent mediation services when needed, and for trauma-informed training. While these complexities remain unaddressed, services will likely continue to inflame serious situations or refuse to work with people who need it most.

Case Study

Following on from the previous Case Study, it is clear to VALID that this person with disability is considered 'difficult' to work with by various professionals. This should not affect the duty of care the person receive, but it does.

Their family member is also responding to providers from a place of trauma, which is being interpreted by professionals as 'difficult' behaviour. The NDIS Q&SC staff response is to further inflame an already difficult situation by invalidating this person's experience.

The person with disability has now had to engage a new Support Coordinator and request further, different supports from the NDIS due to a complete breakdown in their previous working relationships.

This Case Study speaks to an urgent need for better trauma-informed training and support for service providers, Support Coordinators and NDIS Q&SC staff in how to handle, de-escalate and later debrief on situations where they might be verbally abused by people with disability and their burned-out family members.

VALID Recommendation 10

Legal changes to restraint of people with disability (**Volume 6**) must be considered alongside changes to disability support provision that focus on the capacity of professionals to support people with disability and their families when in crisis. This should include a significant focus on the provision of high-quality trauma informed support for people with disability, their families and their support professionals.

Funding for state-based advocacy services falls well short of what is needed to implement the DRC Recommendations.

Without appropriate levels of predictable and sustained funding for state-based advocacy services, some of the DRC Recommendations would be difficult to implement in practice. For example, with the current level of funding allocated to state-based advocacy services, **DRC Recommendation 11.3 ('One-stop shop' complaint reporting, referral and support – c. with a person's consent, make warm referrals to advocacy and other services who can support them in the complaint process)** would likely result in many people waitlisted or turned away from much-needed advice and support.

With appropriate funding advocacy services could support more individuals, and engage in more research and systemic advocacy, to begin to dismantle the structures that maintain violence, abuse, neglect and exploitation against people with disability. These services could also work with support providers to improve the providers' practice. Appropriate funding for advocacy services would result

in higher levels of support, and more effective support, for people with disability, their families and service providers.

VALID supports Disability Advocacy Network Australia (DANA)'s campaign to increase funding for independent advocacy. For more information on the campaign: speakupadvocacy.com.au

---

Case Study

Following on from the previous Case Study, there were many intersecting issues that VALID could have worked with the person with disability and their supporters at an early stage to resolve. However, due to funding constraints, VALID was contacted long after the situation had escalated and had to concentrate on a single issue even though this issue was impacting, and being impacted by, other complex issues.

VALID Recommendation 11

Funding for independent advocacy organisations who directly support people with disability should be significantly increased. (Source: speakupadvocacy.com.au)

List of VALID Recommendations

Recommendation 1

Federal and State Governments should work together to ensure a cohesive, fair approach to supporting parents with intellectual disability to raise their children in safe and loving homes.

Recommendation 2

If DRC Recommendation 7.14 is accepted by the Government, safeguards, sector and community responses to issues and challenges need to be developed. These responses should minimise or eliminate negative impacts on students with disability and the community. Implementation of **DRC Recommendation 7.13** should address this.

Recommendation 3

If the Government accepts **DRC Recommendation 7.24**, mental barriers and people's psychological capacity to engage in a given role should be considered alongside those already identified by the Commissioners.

Recommendation 4

Supporting people with disability to understand the current infrastructure that supports open employment is a good start. VALID's recommendation is that sustained and co-designed efforts are undertaken to improve this infrastructure. This infrastructure includes but is not limited to Centrelink and Disability Employment Services (DES).

Recommendation 5

DRC Recommendation 7.17 needs to include a practical focus on ensuring that DES are equipped, willing and ready to competently support people with higher support needs into open employment.

Recommendation 6

Funding structures to increase open employment opportunities for people with intellectual disability should be carefully designed in consultation with people with intellectual disability, their supporters, employers and government.

Recommendation 7

If the Government accepts **DRC Recommendation 7.31**, it needs to direct its implementation with deep understanding of and practical responses to the potential unintended consequences.

Recommendation 8

If the Government accepts **DRC Recommendation 7.32**, it needs to direct its implementation with deep understanding of and practical responses to the needs of people with intellectual disability with higher support needs.

Recommendation 9

Legal changes to restraint of people with disability (**Volume 6**) must be considered alongside changes to the NDIS Q&SC that focus on their capacity to support people with disability, their families and support networks when in crisis. This should include a significant focus on the provision of high-quality trauma-informed support.

Recommendation 10

Legal changes to restraint of people with disability (**Volume 6**) must be considered alongside changes to disability support provision that focus on the capacity of professionals to support people with disability and their families when in crisis. This should include a significant focus on the provision of high-quality trauma-informed support for people with disability, their families, and their support professionals.

Recommendation 11

Funding for independent advocacy organisations who directly support people with disability should be significantly increased (Source: speakupadvocacy.com.au).